

Did you know that more than 40 organizations are banding together to work for you?



For more information about the Hawaii Caregiver Coalition, please contact:

Wes Lum

Hawaii Caregiver Coalition
c/o Executive Office on Aging
250 S. Hotel Street, Suite 406
Honolulu, Hawaii 96813

E-mail: wes.lum@doh.hawaii.gov

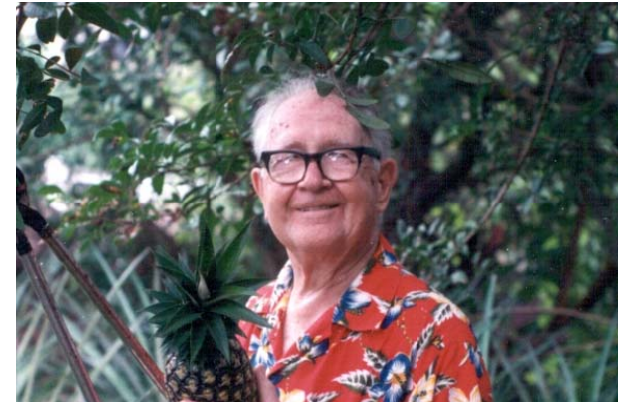
Phone: 808-586-0100

The **Hawaii Caregiver Coalition** represents the following organizations:

AARP
Alu Like
Alzheimer's Association
Castle Hospital's Caregiver Support Group
Central Oahu Caregiver's Support Group
CHOC Support Group
Developmental Disabilities Council
Eldercare Hawaii
Eldercare Support Group
Elderly Affairs Division, City & County of Honolulu
Executive Office on Aging
Good Beginnings – County of Maui
Hawaii Alliance for Retired Americans (HARA)
Hawaii Community Caregiver Network
Hawaii County Office of Aging
Hawaii Family Services
Hawaii Intergenerational Network
Hi'i Na Kupuna – Maui's Caregiver Coalition
HMSA
Honolulu Gerontology Program
Hospice Hawaii
HSTA-Retired
Hui Malama Learning Center
Kapiolani Community College
Kauai Agency on Elderly Affairs
Kokua Council
Kokua Mau
Legal Services for Children
Maui Adult Day Care Centers
Maui Association for Family & Community Education
Maui County Office on Aging
Na Tutu
Neighborhood Place of Wailuku
Northshore Family Caregiver Support Group
Policy Advisory Board for Elderly Affairs
PATCH - Maui
Project Dana
Queen Liliuokalani Children's Center
UH Center on Aging
UH Cooperative Extension
UH FACS Department

Hawaii Caregiver Coalition

Improving the quality of life for those who give and receive care.



HAWAII CAREGIVER COALITION



HOW DID WE GET STARTED?

The *Hawaii Caregiver Coalition* was formed to develop new partnerships at local and state levels to advance a coordinated approach to address the needs of Hawaii's family caregivers.

OUR VISION

Caregivers in Hawaii are recognized, supported, and valued by the community which provides access to affordable, quality resources and services, thereby enhancing the lives of our 'Ohana.

OUR MISSION

As caregiving touches everyone, the mission of the *Hawaii Caregiver Coalition* is to improve the quality of life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education, and outreach.

OUR GOALS

(1) Hawaii caregivers will be well-informed and organized into a caregiver network to better care for their loved ones and themselves.



(2) To identify gaps in services, to support projects and existing laws and policies, and to advocate for service expansion and policy formulation to fill those gaps.

(3) To promote education and outreach to non-professional caregivers, professional caregivers, the public at-large, and policy makers regarding caregiver needs, resources, and best practices.



ADVOCACY ISSUES - 2006

- ◆ Training & Education for Family Caregivers
- ◆ Caregiver Recognition
- ◆ Financial Incentives (i.e. Tax Credits or Reimbursements)
- ◆ Expanded Respite Services
- ◆ Balancing Caregiving and Employment
- ◆ Grandfamily Caregiving

SUPPORTING OUR COMMUNITY IN 2005

- ◆ 2005 Legislative Thank You Reception
- ◆ Family Caregivers Speakers' Bureau
- ◆ Family Caregiver's Kit

FACTSHEET: WHO ARE THE CAREGIVERS IN HAWAII?

Definitions:

- The term *caregiver* refers to anyone who provides assistance in some capacity to another in need – a frail or ill elder, a grandparent raising their grandchild, or a person of any age with physical or cognitive disabilities.
- *Informal caregivers* or *family caregivers* are terms that refer to unpaid individuals including family members, friends, or neighbors providing full- or part-time care, living with the person being cared for or living separately. Informal caregiving is often referred to as the “backbone of long-term care.”
- *Formal caregivers* are volunteers or paid care providers.

Who Are Hawaii’s Family Caregivers?

Overall, persons in different demographic groups and with different socioeconomic characteristics exhibit a remarkably similar likelihood of being caregivers.

Magnitude

- An estimated 14% to 21% of adults, or 126,598 to 192,390 individuals, in the State provide regular care or assistance to a person aged 60 years or older.^{1 2}

Age

- Persons in the 55-64 age group are most likely to be caregivers,

with approximately 1 in 5 persons saying that they provide care or assistance to someone 60 years old or older.³

- Persons below their mid-30s are least likely to be caregivers.⁴

Gender

- Similar proportions of men and women (12% and 16%, respectively) report that they provide care or assistance to someone 60 years old or older.⁵
- Although men are almost as likely as women to report that they provide care, several national studies have found that women are more likely than men to be primary caregivers, and that women are more likely than men to provide caregiving of higher intensity and frequency.^{6 7}

Ethnicity

- Among the different ethnic groups in Hawaii, Native Hawaiians are most likely to provide care or assistance to an elderly person (18%); Caucasians are least likely to provide care (11%).⁸

¹ Hawaii Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

² Hawaii Department of Health. *Hawaii Health Survey*. 2003.

³ Hawaii Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

⁴ Ibid.

⁵ Ibid.

⁶ National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

⁷ The Henry J. Kaiser Family Foundation, et al. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-term Care from the Caregiver's Perspective*, 1998. 2002.

⁸ Hawaii Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

Marital Status

- Married persons are as likely to provide care or assistance as their unmarried counterparts (approximately 14% of married and unmarried persons are caregivers).⁹

Employment Status

- A higher percent of unemployed than employed persons say that they provide care or assistance to an elderly person.¹⁰
- This rate of unemployed caregivers is consistent with findings of national studies that some caregivers resort to quitting their jobs or altering their employment arrangements to accommodate their caregiving responsibilities.¹¹

Household Income

- Adults of any household income in Hawaii have a similar likelihood of providing care or assistance to an elderly person.¹²

Caregivers vs. Their Non-Caregiving Counterparts

- To get a clearer picture of Hawaii caregivers and their demographic, socioeconomic, and health characteristics, it is prudent to compare caregivers with non-caregivers.
- Hawaii Caregivers are remarkably similar to their non-caregiving counterparts in the State in terms of age, ethnicity, education,

income, household size, health, and other characteristics.^{13 14}

- The characteristics of Hawaii caregivers are very similar across the four counties.¹⁵

Characteristics of Care Recipients

Place of Residence of Care Recipients

- 20% of Hawaii caregivers care for a person who lives in the same household. This pattern is similar in all four counties.¹⁶

Relationship Between Caregivers and their Care Recipients

- In Hawaii, among caregivers and care recipients living in the same household, the person most likely to provide care to an older person is a spouse or partner (29% of caregivers), an adult child (21%), or other relative (22%).¹⁷

Many caregivers do not self-identify themselves as such, thereby incurring major implications for program and service planning delivery, as well as data collection and interpretation:

- ~ High numbers of caregivers that do not self-identify themselves as such imply that estimates of the number of people who are caregivers are likely to be underestimated.
- ~ Self-identifying as a caregiver has important complications: those who acknowledge their role are more proactive in reaching out for resources.
- ~ Not self-identifying may foster relative invisibility of caregiver issues at the state level.
- ~ Not self-identifying may impede with caregivers' empowerment in the communities and limit opportunity for their recognition in the state.

⁹ Ibid.

¹⁰ Ibid.

¹¹ National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers*. Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.

¹² Hawaii Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

¹³ Ibid.

¹⁴ Hawaii Department of Health. *Hawaii Health Survey*. 2003.

¹⁵ Hawaii Executive Office on Aging. *Family Caregivers: A Summary of National and Local Data*. December 2004.

¹⁶ Hawaii Department of Health. *Hawaii Health Survey*. 2003.

¹⁷ Ibid.

Hawaii Caregiver Coalition

Improving the Quality of Life for Those Who Give & Receive Care

PUBLIC POLICY PRINCIPLES FOR CHANGE: TRAINING & EDUCATION

Outcomes: Family caregivers will have ongoing education and training in order to meet their caregiving responsibilities and to be advocates for their loved ones.

Strategy: Partner with State and County agencies and other stakeholders to provide education and training to family caregivers such as developing caregiver training centers in the Community Colleges and the production of multimedia, DVD's, webpages, etc. as possible modes of communication.

Background:

- Family caregiving is a complex responsibility involving emotional support, household management, medical care, dealing with a variety of governmental and other agencies, and decision-making. Yet family caregivers consistently report that they are not prepared for these roles. This lack of training occurs throughout the caregiving experience, but is most apparent when care recipients are discharged from hospitals or short-term nursing home stays after an illness or accident. Families are expected to perform skilled nursing care, but without the training that professionals must receive.
- Family caregiver needs for information and training change throughout the course of their loved one's illness. They must have opportunities to learn new skills as they become necessary, access new resources, and learn about care options as the situation changes. Family caregivers need help with the basic skills for assisting their loved ones in areas such as: lifting; transporting; CPR; bathing; learning to deal with loved ones with dementia; coping and other related psychological skills and emotional support; communication skills to help them deal with concerns expressed by their loved ones; and selecting and using of various aids that are available.
- Hawaii's long-term care workforce shortages and its impact will become increasingly difficult on families as the aging population increases. The demand for services for individuals needing long-term care will outpace the supply of care workers and will worsen if not addressed.
- Family caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings. Additionally, family caregivers and their loved ones must be assured of an affordable, well qualified, and sustainable eldercare workforce.

Hawaii Caregiver Coalition

Improving the Quality of Life for Those Who Give & Receive Care

PUBLIC POLICY PRINCIPLES FOR CHANGE: RESPITE SERVICES

Outcome: Family caregivers will have access to respite care as a key component of the supportive services network.

Strategy: Support initiatives that promote respite care.

Background:

- Respite care addresses one of the most pressing needs identified by families, namely temporary relief to reduce the strain that caregivers experience on a day-to-day basis. Respite services are primarily to provide substitute support for care recipients in order to provide a period of relief or rest for the caregiver. Respite care can allow time for the caregiver to, for example, address their own personal needs, attend a class to learn caregiving skills, participate in a support group, take care of other business, or attend to an unexpected emergency.
- Respite decreases the individual and family stresses associated with caregiving. It benefits both the caregiver and care recipient. Respite care can relieve the burden of the caregiving situation and allow families to continue to care for their loved ones who would otherwise have been placed in a nursing home. Respite services can be provided at home or in a group or institutional setting such as adult day centers, nursing

homes, respite camps, and other facilities.

- Although the need for respite services is a priority for many caregivers, respite remains in short supply or are inaccessible to the family for reasons such as attitudes about respite services, eligibility requirements, geographic barriers, cost, or the lack of culturally sensitive programs.
- Family caregivers must have access to affordable, readily available, high quality respite care as a key component of the supportive services network.

According to The State of the States in Family Caregiver Support: A 50-State Study (2004):

~ Respite is the service strategy most commonly offered to support caregivers and is available in all 50 states, although the amount of respite to family members varies substantially from state to state and program to program within states.

~ The most common types of respite offered in state programs are in-home respite, adult day services, and overnight respite in a facility.

Hawaii Caregiver Coalition

Improving the Quality of Life for Those Who Give & Receive Care

PUBLIC POLICY PRINCIPLES FOR CHANGE: FINANCIAL INCENTIVES

Outcome: Family caregivers will be supported with financial incentive options to ease the responsibilities of caregiving.

Strategy: Develop financial incentive options to ease the responsibilities of care giving such as reimbursements, caregiver tax credit, and cash and counseling/consumer directed models.

Background:

- While Medicare, Medicaid, and long-term care insurance may cover healthcare costs for many, caregiving families incur significant financial obligations to pay out-of-pocket expenses for their loved ones.
- Families with a loved one with a disabling or chronic condition needing help with activities of daily living have out-of-pocket medical expenses which are 2.5 times greater than for a family without a family member with a disabling or chronic condition.
- Family members, primarily women, undercut their own retirement security in many ways. In general, women receive lower Social Security benefits because they had lower lifetime earnings, juggling family and work responsibilities. Part-time work disqualifies them for employer-sponsored retirement plans. If employer-matching contributions are provided, they receive a lower amount due to the lower salary.

- For many caregivers, the ability to save is hindered by a reduction in work hours which result in less take home pay. Over the course of a caregiving career, family caregivers providing intense personal care can lose as much as \$659,000 in wages, pensions, and Social Security over a lifetime.
- Family caregivers must be protected against the financial consequences of caregiving that can put their own health and well-being in jeopardy.

According to The State of the States in Family Caregiver Support: A 50-State Study (2004):

~ States are grappling with ways to improve quality of care, address the shortage of direct care workers, and increase consumer choice. One method of achieving these goals is to pay family members who provide vital care to their elderly or disabled relatives.

~ In states that enable consumers to direct their own services, the freedom to hire a family member, friend, or neighbor is viewed as a meaningful feature of choice and control.

Hawaii Caregiver Coalition

Improving the Quality of Life for Those Who Give & Receive Care

PUBLIC POLICY PRINCIPLES FOR CHANGE: BALANCING WORK & CAREGIVING

Outcome: Family caregivers will be supported by workplace policies to meet their caregiving responsibilities.

Strategy: Support proposals to promote workplace friendly policies such as flextime; work-at-home options; job-sharing; counseling; dependent care accounts; information and referral to community services; and employer-paid services of a care manager.

Background:

- Caring for older relatives incurs costs to businesses as well as employees. It is estimated that U.S. businesses lose between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older. Several studies have documented costs of caregiving to businesses, particularly in terms of the replacement costs for employees who quit due to their caregiving responsibilities; absenteeism costs; costs due to workday interruptions; costs due to eldercare crises; costs associated with supervising employed caregivers; and costs associated with the detrimental impact of caregiving responsibilities on a caregiver's health.
- Employees also incur costs as a result of balancing work and caregiving responsibilities. Studies indicate that working caregivers take leave of absence, change

from full-time to part-time, and take a less demanding job to give care.

Working caregivers also permanently leave the workforce, some of whom do so by taking early retirement and others leave without any retirement benefits.

- The Family and Medical Leave Act (FMLA) is the first national policy designed to help working caregivers meet both their work and family responsibilities. Due to the FMLA, many employees can take up to 12 weeks of *unpaid* leave to care for a seriously ill family member, among others, without losing their job or their health insurance. The benefits afforded under the FMLA are limited, however. For example, the FMLA doesn't cover all workers, only companies with 50 or more employees, and the leave is unpaid, forcing many people to make difficult decisions about how to simultaneously meet the caregiving needs of an ailing loved one and pay the family's bills.
- Family caregivers must be supported by family friendly policies in the workplace in order to meet their caregiving responsibilities.

Hawaii Caregiver Coalition

Improving the Quality of Life for Those Who Give & Receive Care

PUBLIC POLICY PRINCIPLES FOR CHANGE: COORDINATED SERVICES & POLICIES

Outcome: Family caregivers will have affordable, readily available, high quality, comprehensive services and policies that are coordinated across all care settings.

Strategy: Coordinate family caregiver support services and policies statewide such as developing a single access system and enhancing access to case management services.

Background:

- People who need the assistance of family caregivers typically have complex, chronic medical conditions and functional limitations. As a result, they require services from many parts of the medical and long-term care system. Unfortunately, coordination of information and services within each system and between these systems rarely occurs.
- Eligibility requirements, service complexity, and fragmentation are the top barriers to coordinating caregiver support programs with other home and community based service programs.
- To strengthen caregiver programs, it is recommended that there be more innovation in program design to provide a broader array of services, better coordination, and integration of caregiver support into home and community based services, and more local collaboration.

- In 2000, 50% of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62% reported that different providers gave other conflicting information. Another recent survey found that 44% of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24% stated poor care coordination can lead to otherwise unnecessary nursing home stays.

According to The State of the States in Family Caregiver Support: A 50-State Study (2004):

~ Respondents call attention to the fragmented nature of long-term care services and stress the need to integrate caregiver support into the home and community based services (HCBS) system, making the delivery of caregiver services an everyday practice in family-centered home and community-based care.

~ "Don't look at caregiver programs in a silo," recommends one National Family Caregiver Support Program respondent. "Integrate caregiver support into other HCBS programs."